

Sense

The National Deaf-Blind
and Rubella Association



**ANNUAL
REPORT
1983-84**



Sense

The National Deaf-Blind
and Rubella Association

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From the Chairman of Sense Jessica Hills

For me, 1983 was a breakthrough year in which the Association made clear its intention of ensuring the maximum provision of services to its beneficiaries. This meant a coal appraisal of its organization and management, the formulation of a plan of action and the implementation of that plan.

An act of retrenchment was first of all needed, and the closure of our School Unit at the Family Centre and its transfer to the Royal School for Deaf Children at Margate paved the way for a realistic development of the Association's activities.

The Development Plan presented at last year's AGM has already been put into practical effect. The appointments of David Brown and Doreen Narris have meant that a Peripatetic Advisory Teaching Service is now available to much of the country. We

intend that during 1984-85 this service will be extended to all of England and Wales.

Peggy Freeman's spirited proposal last year for fuller parent involvement in the Association's everyday affairs led to the appointment of Norman Brown to a post at the Gray's Inn Road HQ - the first paid parent worker in our history. Together with Paul Ennals, Norman is now helping to push forward activity in the area of Rehabilitation and Community Care for deaf-blind and rubella-handicapped adults, and to develop our holiday and respite services. We are also on the brink of stimulating local action, both in the formation of groups and in linking parents.

The enormous improvement in our financial position has been made possible by some extremely hard work throughout the year. My thanks go particularly to Admiral Sir Raymond Lygo - an extremely active Appeal President with a very busy life as Managing Director of British Aerospace plc, and to Commander Charles Dewey. Together they have headed a most vigorous and successful appeal. I cannot begin to quantify the enormous contribution made by members and staff during the year, so I would merely record here my deepest appreciation of the efforts of one and all.

**Admiral Sir Raymond Lygo, KCB,
Sense's Appeal President with Mandy
at the Family Centre**



A New Structure for SENSE

The proposal that the Association should seek corporate status was first raised in a review of its constitution and activities which we commissioned from Mike Hudson, a management consultant, recommended by the then newly-formed Management Services Unit of the National Council for Voluntary Organisations. This report was presented to the Council of Management in December 1982.

The main reason for becoming a company is to reduce the risk and personal liabilities of Trustees. Under the Charitable Trust set up in 1975, the five Trustees are personally liable should the Association incur debts or, for example, have to meet a substantial claim by a member of staff for an accident not covered by insurance. With the scale of operations in 1975, the potential liabilities to be faced by the Trustees were trivial, but in 1984 with 50 staff and an annual turnover of over £300,000, they are very large indeed.

Following the publication of Mike Hudson's report, the Council of Management considered the proposal and suggested to the Trustees that they consider winding up the Trust and setting up a



Moving forward

company. In May 1983, the Trustees met and agreed on this course of action. The 1983 AGM approved the proposal in principle, and last Autumn the Council gave the Policy Group responsibility for drawing up the new Constitution (Memorandum and Articles of Association) and managing the changeover.

The Policy Group – Jessica Hills, Margaret White and Tony Best – met regularly throughout the winter and retained Mike Smyth of Knapp-Fishers, Solicitors, to undertake the legal aspects. Continuous discussion took place with the Charity Commission, the Inland Revenue and the Registrar of Companies, and by February 1984 the new Constitution was finally agreed. It was received and approved by the Council at its March meeting and signed by the subscribers of the new Company at the end of April.

The eight subscribers are the original Trustees – Margaret Brock, Peggy Freeman, Jessica Hills, Derrick Roper, and George Williams – plus three others. Because the first subscribers also comprise the Council of Management until the 1984 AGM, and because the new Constitution requires a minimum of eight people for the Council, a further three people were required. Three long-standing members agreed to make up the eight – Tony Best, Gini Cloke and Margaret White.

The 1984 meeting in July will be the last AGM of the Charitable Trust. It will differ from previous AGMs in that there will be no elections. The Council of Management from that time will be the directors of the new Company and they will be appointed by the 8 subscribers. Council membership will be for a maximum of three years, with one third of the Council retiring each year. Therefore, after 3 years (ie by the 1987 AGM) the Council will be a fully elected body. The main business of the 1984 AGM will be to consider the transfer of assets and responsibilities of the old Charitable Trust to the new Company.

The main elements of the new Constitution are as follows:

Proposed Memorandum of Association (ie what we do)

- **Objects** To support and promote the interests of people who have vision and hearing impediments or persons who are functioning as such or persons who are suffering from the congenital effects of rubella."
- **Powers** As wide as the Charity Commission will allow.
- **Subscribers** The company will be set up by 8 members who will be the Trustees of NADBRH (the old organisation), plus three others.

Proposed Articles of Association (ie how we do it)

- **Members** Paid-up members are ultimate controllers of the organisation. A register of paid-up members must be kept. All members must be informed of Annual General Meetings and Extraordinary General Meetings. Members can appoint proxies to attend on their behalf.

- **AGMs** There must be one per year. They will be called by the Council. Twenty-one days notice must be given. Motions must be submitted to the Secretary in time for all members to be informed of them. A quorum will be 25 members.

- **Chairman** Elected by members at AGM. Presides over AGM and Council of Management. Cannot vote unless votes tie. Has a three-year term of office.

- **Council** Between 8 and 16 paid-up members. The first Council to be chosen by the Subscribers (see above). Subsequent Council members to be elected by the Membership. Members to have a 3-year term of office.

Council membership to be withdrawn if member is:

- bankrupt
- insane
- does not pay membership fee
- voted off by other members
- does not attend four consecutive meetings

Vacancies to be filled by co-option. A quorum is 6 people. Papers must be sent out 6 days before the meeting.

- **Retirement and Re-election of Council Members** A third of the Council retires each year. The longest serving members retire first. Council members are eligible for re-election. Nominations must be proposed in writing and the proposed person must give their written consent.

Proposed Transition Process

- Council approves Memorandum and Articles of Association.
- Final Charity Commission approval received.
- Trustees meet to sign the Memorandum and Articles and to select the first Council.
- New Council holds its first meeting. Receives proposed plan and budget from the director. Sets up Committee structure eg Executive Committee, Manor House Committee, etc. Sets up Advisory Council.
- AGM hands over assets, staff, membership, etc to new organisation. AGM confirms new Council.

Sense's Work 1983-1984

Family Support & Services

The Family Centre

The Family Centre's main work since Easter 1983 has been support for young deaf-blind children and their families. Within the context of a service individually tailored to each family, the Family Centre provides a peripatetic service in connection with a Centre-based service. It is also used: as a place of assessment for both present and future needs in conjunction with programme planning for parents and teachers; a place for the whole family to learn together; a place for teaching sessions; a base for the home teaching service; a place for the interchange of information between parents and professionals; a resource centre; a place for courses (day, weekend and week) and a place for information and advice on welfare and statutory rights.

There are three teachers who undertake the peripatetic work - David Brown (London and the South East), Doreen Norris appointed April 1984 (Midlands area), and Lindy Wyman. It should be stressed that the peripatetic service and the Centre-based service are not mutually exclusive. The dynamic between them is complex but it can be stated that rarely will a family only be offered either one or the other. During the last few months, through a process of organic growth, several aspects of the Centre-based service have developed, most important of these being parents' weekend workshops which provide the parents with the opportunity of learning together about the development of young deaf-blind children, with special reference to their own child. The workshops have also provided a forum for a group of parents of young children out of which have evolved ideas for the Parents Newsheet and requests for more courses, group meetings etc.

In addition to the development of the peripatetic advisory service for the parents of young deaf-blind children, the Family Centre has expanded its work in other ways:

- Centre staff are planning to build up the resource aspect of the Centre so that we will have a much enlarged and permanent display of useful equipment - toys, videos, pamphlets and books for use by parents and professionals.
- Our holiday schemes for children under the age of ten have proved so popular that we now have schemes running each half-term as well as in the long summer holiday.



Learning ...

... to let go



● We have been able to run three courses for professional people working with young deaf-blind children during the past year, and we are now being asked to organise courses in different parts of the country for those professionals who are unable to travel to London for the courses.

Regional Activity

Plans are underway to extend the local structure of the Association - to allow increased communication and to improve the services we can offer to our members. The regions continue to run regular meetings, organise the caravans, hold fund raising events and provide the support needed for the families. But it has long been felt that each region represents too large an area for our dedicated regional organisers to cover, and that we should extend the services we offer by developing a network of local branches.

This increase is now being planned for: First, we intend to multiply the number of local branches, encourage new members to become involved in their local group and support each new group in their efforts to gain local support. And second, we will form a 'Contacts Network' so that members in any part of the country will have someone local to refer to for information or advice.

We hope that these measures will allow close and regular involvement of all parents in the affairs of the Association, as well as extending the number of members.

Scottish Report

The main concern of the Scottish region has been the opening of the new school. By this summer we hope that 6 children presently settled at St. Vincent's School will have settled into the new school at Carnbooth. Some details still need to be settled, but we are all optimistic that things will go well.

We have also had a lot of publicity lately: Sheena Tulloch has been on both



Family Centre Workshop

radio and television, and Gill Morley participated in a ten minute TV spot. This has resulted in a number of new contacts, both from parents and professionals.

Fundraising has continued well, with a steady income provided from a number of bottles in pubs, supplemented by sales and extra donations. Much of this success is due to the work of Mr. and Mrs. Cox. The caravan was fully booked and was ably run by Linda and Tim Collins.

Future work includes contacting all the local authorities in Scotland, providing information about the Association and seeking more details of the true numbers of deaf-blind young people. We also want to set up displays to exhibit around schools and hospitals in aid of the Rubella Campaign and to advertise the services which already exist for deaf-blind children. Also we want to go further in our plans for a residential project for school leavers and to strengthen our links within the deaf and

blind communities as well as working more with the Autistic Association.

Holidays

The summer of 1983 saw two summer holidays organized for our children. Chris Best and her team took the older ones to the Sunshine Home in Southport for a fortnight whilst the Family Centre in Ealing provided the base for holidays for many of the younger ones. For 1984, plans are in hand to meet a wider need and the first Association holidays for deaf-blind young adults are taking place. Norman Brown took the first group to Caister for a week, and Buckinghamshire will be the venue for the second adult holiday in August. As usual, the Family Centre and Southport holidays are heavily subscribed. The Association's caravans in Wales, Scotland and Lincolnshire continue to provide enjoyment for many of our members.

Education

The nature of educational services specifically geared to deaf-blind children changed dramatically during 1983. The falling birthrate in recent years brought about the closure of many schools for deaf children and blind children. The running down of schools within mental handicap hospitals has signalled the end of the units for the more severely handicapped deaf-blind child. The general fall in child population has meant that existing units have been forced to modify their criteria in order to remain viable, and these units now serve a wide range of multiply handicapped children with sensory impairments.

The Association has long been concerned that deaf-blindness did not constitute a special category within Special

Education, unlike deafness, blindness, physical handicap, maladjustment etc. As a result, specific provision for deaf-blind children has not been mandatory upon Local Education Authorities and it has, therefore, been scanty. The removal of categories in the 1981 Education Act has so far done little to improve the situation and during the past years provision has fluctuated more than ever before. SENSE has always produced an annual list detailing some 12 units providing especially for deaf-blind pupils. By 1983, the number had been reduced to three: Conover, St. Vincent's Glasgow, and Whitefield East London, the remainder having closed or broadened their criteria.

Royal Victoria School for the Blind, Newcastle

The Multiply-Handicapped Unit at RVSB Newcastle is held in high regard by the many parent members of the Association whose children have passed through its doors. The marked increase in the numbers of multiply-handicapped children measured

against a decrease in children with a single handicap is mirrored at Newcastle where a thriving unit is centred within a school whose numbers only just allow it to be viable. It had long been expected that the school would close by July 1985, and we were thunderstruck to learn early in 1984 that the Governors had decided on a July 1984 closure. Immediate pressure brought by SENSE and other interest groups at a high level brought about a reversal of this decision and consideration is now being given both locally and at the Department of Education and Science to the future of the school, to what service will be available to blind and multiply-handicapped blind children in the north of England and on the need for a new setting for the unit.

Whitefield School, Walthamstow

Tony Best and Rodney Clark were invited during the year to sit on a working party whose purpose was to report on the construction of a new permanent building to house the Deaf/Visually Handicapped Unit

at Whitefield School. The unit is currently housed in a number of pre-fabs on the site and its continued expansion now requires a purpose-built annexe to the school where facilities and access will allow the wonderful work carried out there to be more effectively promoted. The report was produced by Easter 1984 and is now with the Whitefield Trustees who have undertaken to find the capital required.

Regional and National Plans

As reported in the 1982-83 Annual Report, the Government has been attempting to plan educational services for deaf children and for blind children by seeking strategic plans from Regional Standing Conferences which were to result in the publication of National Plans. These are still awaited. SENSE's attempt to secure planning for deaf-blind education within these plans has probably met with only limited success, but the DES have indicated that a separate plan for this 'category' would seem preferable and we are, therefore, seeking a wide range of information to encourage and then feed a formal enquiry. Chris Best's survey of deaf-blindness in English ESN(S) schools, evidence from the Family Centre of the 80+ pre-school children with whom the Centre is in touch and other evidence has already been lodged at Elizabeth House.

The Education Act 1981

SENSE has been involved in "statementing" procedures for many of its members, principally the pre-school children with whom the Family Centre is working. It is still very early to assess the effects of the Act and the new procedures, although there is

some guarded optimism that parents are being allowed to play a greater part in the process. We have taken up the case of a number of families whose LEAs have not changed their ideas or their traditional exclusive practices with the change of legislation. One major concern is that parents are still not being drawn into the process early enough and that LEAs are appearing to give little attention to the appointment of "named persons", the catalyst for positive action which was promoted so strongly in the Warnock Report.

Professional Training

The Education Committee, concerned at the lack of training in multi-sensory impairment, organized a seminar of interested organisations to discuss the setting up of a post-graduate course. Arising from this, a working party was set up, consisting of representatives from the British Association of Teachers for the Deaf, The Association for the Education and Welfare of the Visually Handicapped and SENSE. The working-party has produced an outline course and has recommended that it should be full-time for one year at the Advanced Diploma/B. Phil level, for experienced teachers who have spent at least a year working with a multi-handicapped child who has a sensory impairment. At the time of writing, approaches are being made to seats of higher education to gauge the interest in adoption of the course.

Education Committee

In addition to its involvement in all the issues above, the Education Committee has been

active in a number of key issues during the year. These include:

- Making training films and videos for teachers and parents.
- Preparations for a short course for teachers.
- Organisation of a September 1984 Conference for parents and teachers.
- SENSE's contribution to the August 1984 New York Conference of the International Association for the Education of the Deaf-Blind.
- A conference for teachers in November 1984 on hearing loss in the profoundly handicapped child.

The committee held a conference for teachers on 'The Profoundly Handicapped Multi-Sensory Impaired Child' at Birmingham University in June 1983 at which some 90 delegates heard stimulating papers from Judy Bell, Peripatetic Teacher of the Visually Handicapped in Walsall; Tany Best and Darren Harris on Training Approaches, and Heather Janes and Joanne Shields, both Senior Advisors with the Royal National Institute for the Blind, on Stimulation and Motivation.

Green Park Course

April 1984 saw the staging of a five day course for teachers run in conjunction with Mobility International and the Royal National Institute for the Blind, at Green Park Centre in Buckinghamshire. Staff and young people from 10 centres around the country attended the residential course on 'New Techniques for Working with Deaf-Blind Young People' where they enjoyed workshops run by Anne-Margret Pretz from Germany, Uffe Davidson from Denmark and Tany Lumley and Georgette Bullen from England. The success of this week has encouraged us to plan further such courses.

Young Adults

The Manor House

This past year we have concentrated upon building onto the solid foundations of a consolidated course. We have responded to the many and various needs of the students resident at the Manor House. We always need to work upon the previous experience of our students, and it is a great joy to watch the growth of their confidence and communication skills.

At present we have 13 students resident at the Manor House, and we hope to have two more rooms available soon. We are also well under way with plans for the extension to the Manor House which will provide accommodation and training for a further 8 young adults. This provision is intended for less able deaf-blind young adults, many of whom are placed, at present, in mental handicap hospitals. Clearly, there is a lot of money to be raised before this aim is fulfilled, but we are hopeful that the goodwill of the public will see us through.

The first stage of the new development involves building a swimming pool, for which we have the funds already. This should bring enormous benefits to all our students, particularly those who are less able.

It has been fascinating to see Janet, David and Karen settle into the Lodge (the "gatehouse" in Manor House language) where they have had a chance to live more independently, yet still under the eye of the staff. Their catering, shopping and domestic skills have improved tremendously. However, their social life is still very much connected with the main house, though much time and energy has been spent in encouraging them to develop their "own thing" at the gatehouse. In these early stages, independence can seem very like isolation unless we are very careful.

I feel that we have much to learn about this aspect of the development of our students towards integration and independence. While we are working at orientating our students towards the 'deaf world', in practice we appear to be moving towards establishing friendships with able-bodied people. The Friendship Scheme which June Brooks, our deputy principal, has set up has brought real benefits for three of our youngsters. June has worked one step at a time in building up the confidence of the volunteers, providing information, developing signing skills and ensuring continuity so that the friendships which have started will remain and flourish.

We have also received gratifying

support from the village, and money has been raised for all sorts of equipment. In return, The Manor House must play its part in this relationship, and we intend to share the facilities of the gym and the new swimming pool whenever possible. Most days our students are seen in the village either shopping, jogging or catching the bus to Peterborough, and they appear to be accepted by and large.

Another exciting development for this summer should be the moving of two or three students into sheltered accommodation within the village. This is an experimental project and should give us and the students a chance to take a step towards independent living. We also feel the need for a workshop, off site, for the students who progress to this stage and we hope that such a facility can be developed in the future.

The problems of where our students will go at the end of the course are ever present. We hold regular case conferences on all our students, but it still appears that most students will face great difficulty in finding suitable future placements. Let us hope that things will improve next year in this respect.

There has been a lot of publicity for the Manor House this year: September saw the article in the "Sunday Times Magazine", January produced the story of Dawn Kemsley on "That's Life" and this June a half hour documentary on Yorkshire Television's "First Tuesday" series about Stephen Brown's assessment here.



Work...

... and Play



Care in the Community

For several years now, official government policy has been aimed at providing for the needs of disabled people in the community and moving people out of mental handicap hospitals. This is prompted by a desire to allow all people, however disabled, to lead a life as 'ordinary' as possible. Our 1982 conference 'An Ordinary Life' centred on this.

There are many different views as to what constitutes an 'ordinary life' (who among us likes to be thought of as ordinary?), and many different models as the ideal residential setting for deaf-blind adults. There is usually common agreement that the large mental handicap hospitals are unsuitable, with their low staff ratios, lack of privacy and their institutionalisation. But what to put in their place is not so clear. If the money was available, would we want three-bedded homes or twelve-bedded hostels or what?

The answer must be to look at the needs of each individual separately and think about what kind of life-style would be right for each. For some people, the ideal setting might be to live in a small home with a 'nuclear family' of just two or three other people. For others, a larger 'extended family' might be appropriate. Others are happily placed living with their own families with some extra support.

The perfect choice of where to live also presents problems. Some argue that all deaf-blind people are best living together with other deaf-blind people. Others put the case for mixing the handicaps. The answer, again, must be an individual one; we cannot decide in general terms what is right for ALL deaf-blind and rubella handicapped people. We must look at the person and think about what THEY want and need.

Our targets over the last year have been: 1) To increase the provision for further education and training for deaf-blind school-leavers. 2) To increase the suitable number of long-term residential placements. 3) To increase the quality of support services for deaf-blind adults living at home with their families. We believe that the responsibility for providing these services lies with the statutory authorities: education, social services, or health services. Our task, as a small organisation, is to advise, to encourage and (where necessary) to bludgeon authorities into providing services which are appropriate for our members. Sometimes we may need to take the initiative in setting up a project; when that is necessary we need to co-operate as widely as possible, with other organisations and groups.

Further Education

We will give full cooperation and support to Henshaw's Society in Harrogate, in their project to offer further education places to some deaf-blind young adults. We will continue discussions with other agencies on the prospects of developing a further regional centre.

Planning permission has been received for the extension to the Manor House, which should offer up to 8 new places for less able deaf-blind school leavers.

Long Term Care

Advice and support have been given to a number of local authorities and health authorities in an effort to provide alternatives to long-term hospital care. We have been delighted to support the North East Essex

Health Authority in the establishment of Braiswick Lodge, a 12-bedded community unit for blind and deaf-blind residents of mental handicap hospitals. Other areas may well learn from the example given here of providing a highly-staffed specialist unit where specific skills can be developed for working with deaf-blind residents.

We are helping a number of local authorities with their plans for staffed homes for small family units of deaf-blind adults, by providing help with assessment, placing and staff training. The next year should see many of these projects bear fruit with a number of new units due to open.

Contacts are also being established with some existing units caring for handicapped people, with a view to offering the necessary support and training to allow them to accept deaf-blind residents.

Individual Support

Often families or professionals need expert guidance as to where a young person can move on to. SENSE staff have provided such advice to a large number of people, and have represented parents in their dealings with local authorities. We have also helped put parents into contact with the various local services which may be available to help them at home.

Over the next year we hope to initiate several new projects and persuade a wider range of health and social services departments to consider seriously the special needs of deaf-blind people. We also hope to contact more organizations working in related fields, and establish a training programme to support units who accept deaf-blind residents. We hope to build up a comprehensive information bank, centres which offer appropriate care, and to inform a wider range of units of the needs of our young people. Finally, we hope to support more families in their desire to find the best possible care for their children.



David at the Manor House on his independence programme... but what comes next?

Information and Public Awareness

Information

An ever increasing flood of requests for information arrive at the office, and we have tried to answer them all to the best of our abilities. The Rubella Campaign and the

television and newspaper publicity have led to a dramatic increase in requests from students, and we feel it an important part of our job to educate as many people as possible to the needs of our young people, as well as to the importance of rubella vaccination.

A series of information sheets are planned to supplement the information produced in our quarterly Newsletter, 'Talking Sense', as an aid to all those working with deaf-blind or rubella handicapped people.

Rubella Campaign

Together with 10 other national voluntary organisations the Association formed a Consortium to plan a campaign to eradicate Congenital Rubella Syndrome from the land. The project met with considerable success during 1983 when the government agreed to fund the appointment of a Campaign Co-ordinator and the production of publicity material, and HRH The Princess of Wales graciously consented to become Patron of the National Rubella Council, a body composed of the 11 Consortium Organisations, the Health Education Council and the Government Health Departments of England, Wales and Northern Ireland.

To launch the campaign, a major ministerial press conference was held in late November 1983 at Old Admiralty House in

Whitehall, headed by Health Minister Kenneth Clarke. There was extensive newspaper, TV and radio coverage of the conference and the subsequent reception at Lancaster House at which HRH the Princess of Wales met representatives of all the organisations promoting and supporting the campaign.

So far, very little money has been available for the promotion of the campaign, and yet early evaluations of its effect have been very positive. Rubella has featured prominently in national and local press which have reflected the large amount of local spontaneous activity inspired by the national effort. A number of radio and TV programmes have also featured Rubella: "Medical Express", "That's Life" and Yorkshire TV's "First Tuesday" series.

The main thrust of the campaign has been to organise regional conferences within each Regional Health Authority. The strategy is that, following each conference, Regional Action Committees, comprised of the same mix of statutory and voluntary bodies will be set up to stimulate activity within each District Health Authority. So far, two successful conferences have taken place - in Yorkshire and the North West Thames region. Further conferences are planned for the autumn of 1984 and for 1985.

In addition to the printed publicity material, films and videos aimed at both



HRH THE PRINCESS OF WALES, Patron of the National Rubella Council, with the Rt Hon Norman Fowler, Secretary of State for Health and Social Services and Mr Kenneth Clarke, Minister of Health at the launch of the National Rubella Campaign.

schoolgirls and adult women are currently being made and a bi-annual New I "Uptake" has been launched. This effort even more vital as news is reaching us that the Rubella outbreak at 1984 will be as great, if not greater, than that at 1983.

Benefits

We have continued to work on behalf of our members to ensure that they receive all the benefits to which they are entitled. Many families do not know the range of benefits available, and we have succeeded in increasing their incomes by advising on individual cases.

Efforts to increase Mobility Allowance payments to deaf-blind people have continued. Following the decision of the Social Security Tribunal reported in last year's annual report, many members have been successful in their applications by following the guidelines suggested in our leaflet. However, not all members have been successful. There appears to be some discrepancy in the criteria being followed in different areas of the country, so we continue to hope that the DHSS will themselves issue guidelines to clarify this long-running issue.

SENSE, along with other disability organisations, is pressing for a unified Disablement Allowance to rationalise the present confusing structure of benefits. In addition, we have submitted detailed comments on new government proposals on benefits, as they affect our members.

Ushers Syndrome

At the beginning of April 1984, the DHSS informed SENSE that they were able to grant £10,000 p.a. for three years towards the Usher's Syndrome Awareness and Education Programme, during which we hope to achieve two main aims.

1. To create awareness: to let people know that the eye condition at retinitis pigmentosa (RP) exists in a percentage at those born deaf and to alert all those who came into contact regularly with young deaf people. Information will be circulated to doctors, paediatricians, audiologists, otologists and health visitors who deal with blind people. It is also important that teachers and care staff at school are made aware of it so that referrals to an eye clinic are speedy. Usually it is not diagnosed until the student is due to leave school and it is left to the Social Worker for the Deaf to help the young person adjust to the bad news. Social Work Departments therefore constitute an important target group in this part of the programme.

2. To increase understanding: a vital and challenging task fundamentally necessary to the health and welfare of Usher's Syndrome sufferers and their families.

The three year programme, which is based at SENSE headquarters, is also being funded by generous grants from the Royal National Institute for the Blind, the Royal National Institute for the Deaf, the National Deaf Children's Society and the Royal Association in Aid of the Deaf and Dumb.

Legislation

November 1983 saw the debate in Parliament at the Chronically Sick and Disabled Persons (Amendment) Bill, proposed by Robert Wareing, M.P. This Bill

had two sections. The first, which received most publicity, proposed measures for making discrimination illegal by introducing a Disability Commission to investigate possible claims of discrimination. The second, written largely by SENSE, proposed extending the responsibilities of local authorities towards severely disabled people. If passed, the Bill would have introduced an Assessment and Statement Procedure for disabled adults in the same way as the Education Act 1981 did for children, and would, therefore, have involved disabled people and their families more fully in the process of determining what services they needed. It would also have provided a rigorous methodology for establishing people's individual needs and for checking whether social services departments were living up to their obligations.

The Bill was defeated in its Third reading in the House of Lords.

Publications

In conjunction with Bedford Square Press, SENSE have republished "Christopher - A Silent Life" in paperback. Margaret Brock's warm and humorous book about life with her deaf-blind son, was first published in 1976 and deserves the wider audience that this new edition should provide. Margaret has been interviewed about 'Christopher' on both television and radio.

This summer should see the publication of a major new reference work on rubella. Dr. Nick Sidle, previously of the HERA unit at the Spastics Society, has been commissioned to review all the literature on the subject to provide a definitive reference work for serious students. Dr. Sidle's research is unearthing a lot of interesting information. One side-effect of the study will be that SENSE will possess copies of all scientific papers on rubella. We will endeavour to update and maintain this unique resource.

Peggy Freeman's new book on the young deaf-blind child is due to be published soon by Heinemann. It should prove a valuable addition to the scanty material published in this field.

Lindy Wyman, Principal of the Family Centre, is writing a book for Souvenir Press on the work of the Centre, for publication in 1985.

Publicity

This has been a good year for national publicity. The Rubella Campaign generated a vast amount of media coverage from November onwards, and many parent members have provided support for this by telling their story to local newspapers.

In September, the Sunday Times Colour Supplement featured our work at the Family Centre and the Manor House, with a sympathetic story illustrated with stunning photographs by Lord Snowdon. This, as with any national publicity, attracted a lot of interest as well as putting us into contact with several new families.

This January, 'That's Life' told the story of Dawn Kemsley's efforts to be funded at the Manor House. Following the programme her local council agreed to pay for Dawn, and she has now settled down well there.

Yorkshire Television's documentary, 'A Place For Stephen', showed Stephen Brown arriving at the Manor House for assessment and followed his progress through his first three months. The film also dwelt on the parent's angle, through interviews with Stephen's father, Norman Brown.



Margaret Brock and her son Christopher. Margaret's book "Christopher - A Silent Life" received its first paperback publication during the year.



Dawn Kemsley whose story was featured on 'That's Life' in January 1984

HASICOM

SENSE is one of the organisations involved with the Department of Trade and Industry's initiative in developing means of helping people who are both deaf and blind to communicate by telephone. Called HASICOM (Hearing and Slight Impairment Communication) the project currently involves, besides the DTI, SENSE, The Royal National Institute for the Blind, The Royal National Institute for the Deaf, the National Deaf-Blind Helpers League, Breakthrough Trust and, of course, British Telecom. HASICOM has come about as a result

at a similar project mounted two years ago and still in operation, called VISICOM (Visual Communication) which evaluated the different telephone systems emerging for deaf people. From this project developed the idea of using British Telecom's Electronic Mail system whereby, through a central computer, messages can be sent and conversations held with any other user who is using the system at the same time.

The first stage: 7 deaf-blind braille users were equipped with a Versabroaille machine (a computer for receiving, sending, and storing braille messages). With this, messages could be sent to each other and to the organizations involved in the project. Braille machines were also installed at Conover Hall School and at the Deaf-Blind Helpers League. Machines for communicating with these people, using ordinary print, are installed at other locations, including: the Monor House, Groy's Inn Road, R.N.I.B., and the Breakthrough Trust.

The second stage: for those whose friends of communication is Moon, Spartan or similar spelling. This is a much more unknown departure since the technology, unlike the Versabraille, does not yet exist and is being developed. Two linking machines are in development. The first will produce Moon and Spartan on paper tape. Moon is a braille like system but with grosser figures for those whose touch is not sensitive enough. Spartan is simply capital letters printed on the palm of the hand but this machine will require them to read capital letters on tape. A further development will be on electronic hand for finger spelling. For reception, it is intended that the deaf-blind person will place his hand against the machine's hand and receive impulses similar to the feel of the Deaf-Blind Manual.

The third stage: screen enlargers are being evaluated to enable large print users to participate in the scheme.

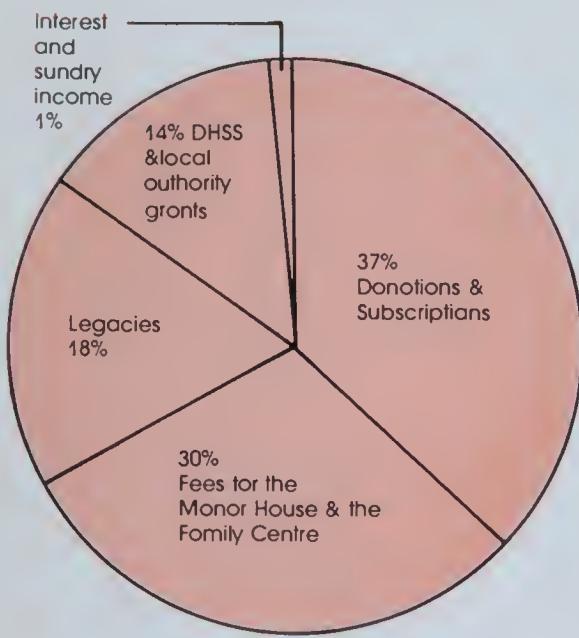
Financial Report

The improvement in our income, anticipated in last year's report, can now be recorded, thanks to a much greater degree of activity in fund-raising. During 1983-84, we sought funds for expenditure not covered by fees or grants and for developing our capital programme. It has been the Association's policy over many years that the provision of rehabilitation and residential facilities for our adult beneficiaries be a major capital priority. Therefore, we were able, during that year, to set aside £150,000 for future capital

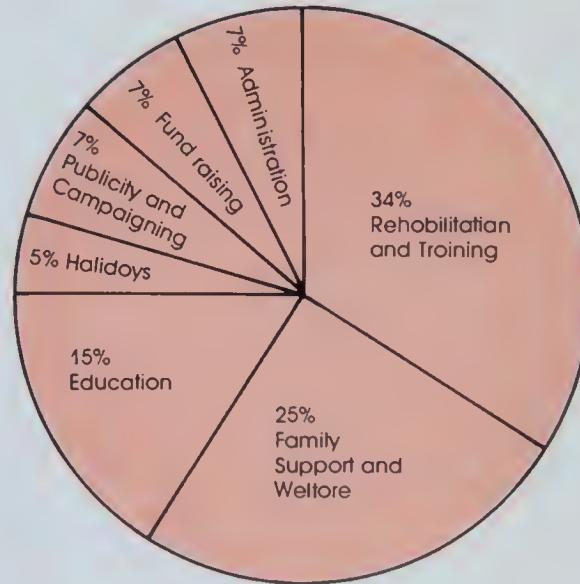
projects. By the year's end we had met all expenditure out of the remaining income save for £6,486, which deficit was transferred to the General Fund.

The diagrams below demonstrate the sources of our total income in 1983-84 and how our expenditure was divided according to function. The proportions are close approximates.

Copies of the accounts for 1983-84 are available from: The Director, SENSE, 311, Groy's Inn Road, London WC1X 8PT.



INCOME



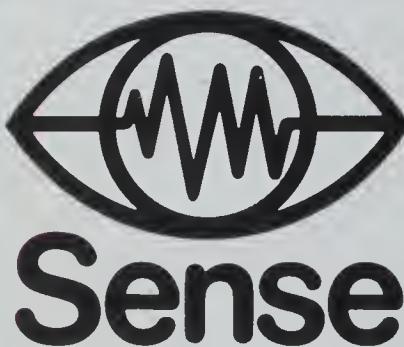
EXPENDITURE

This year we have tried to:

SUPPORT
the needs of deaf-blind children and adults and those handicapped by Congenital Rubella Syndrome.

PROVIDE
services for pre-school and school-aged children and young adults.

PUBLICISE
the needs of deaf-blind and rubella handicapped people, improve understanding of the causes of these conditions and promote the campaign to increase vaccination against rubella.



311 Gray's Inn Road London WC1X 8PT
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WILL YOU HELP US?

Next year we would like to:

ERADICATE
the scourge of rubella handicap in children.

TRAIN
more deaf-blind young adults in a new further education centre.

REMOVE
some of our members from mental handicap hospitals and provide places in the community for them to live.

EXPAND
our pre-school and school advisory service, to have an advisor in every area.

OFFER
a wide range of services to all our members throughout the country.